

Use of Focus Groups to Identify Recruitment and Retention Issues for the National Children's Study

Pauline Mendola, PhD¹, Danelle Lobdell, PhD¹, and Suzanne Gilboa, PhD²

¹ National Health and Environmental Effects Research Laboratory, U.S. Environmental Protection Agency, Research Triangle Park, NC

² National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, DHHS, Atlanta, GA

Research Goals

Through the use of focus groups, the goals for this research were to explore the most effective recruitment and retention strategies for community-based child environmental health research.

The two final reports: www.nationalchildrensstudy.gov/research/methods_studies

Methods:

Assessed three key themes for recruitment and retention:

Phase I Focus Group:

A series of 18 focus groups conducted across U.S. in February 2003

- Expectant parents (10 sessions one in each of the 10 EPA Regions)
 - Varied by geography, maternal age, population density, maternal education, health care provider
- Parents of disabled children (2 sessions)
- Parent of non-disabled children (2 sessions)
- Health care providers (2 sessions)
- Community organizations (2 sessions)

Phase II Focus Group:

Additional 14 focus groups conducted across U.S. in November and December 2003 to explore barriers to participation

- Racial/ethnic groups
 - African American
 - Other Black
 - Mexican American
 - Other Hispanic
 - Native Americans (2 sessions)
 - Asian (2 sessions)
- Teen moms (2 sessions)
- Couples attempting pregnancy (2 sessions)
- Biospecimen collection (2 sessions)

Placeholder for copyrighted image.

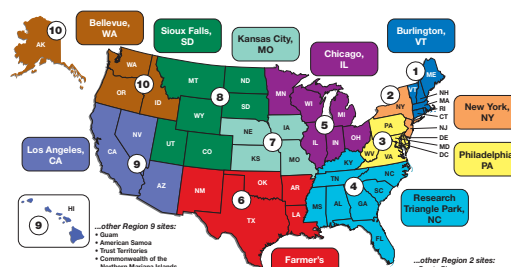
Issues Addressed:

- Getting you interested
 - Where best to hear about National Children's Study
 - Type of information want to know
- Time commitment and data collection activities
 - Schedule of participation
 - Environmental home sampling
 - List of potential biologic specimens
- Keeping you interested
 - Appropriate compensation
 - Stay in touch
 - Information participants want over time
- Barriers to participation (2nd set of focus groups only)
 - Attitudes toward researchers
 - Attitudes toward federal government

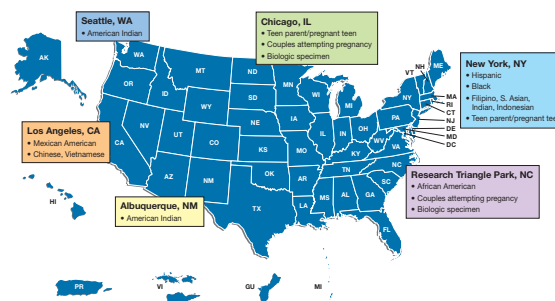
Placeholder for copyrighted image.

Location of Focus Groups

Phase I Focus Group Study Sites – Total 18



Phase II Focus Group Study Sites – Total 14



Results:

Getting You Interested

Themes heard across focus groups

- Doctor's office best place to find out about Study
- Want to know the purpose, details, and risks and benefits of participating in Study
- General excitement about the possibility of Study

New themes revealed in follow-up focus groups

- Engagement (permission) of elders
 - Asian and American Indian – elders within community
 - Teen groups – parents

Time Commitment and Data Collection Activities

Themes heard across focus groups

- Number of visits fine if could piggy back with regular MD visits
- Convenience and options – no one size fits all for questionnaires and home environment sampling

Placeholder for copyrighted image.

Results (continued):

Time Commitment and Data Collection Activities

Biologic sampling

- Urine sample OK
- Genetic testing OK – if explain purpose, provide counseling
- Resistance observed for other types of samples
 - Baby teeth – sentimental reasons (most groups)
 - Placenta
 - Phase I groups – did not understand the need for sample
 - Phase II groups – American Indian group considers placenta very sacred; teens afraid of how will be used
 - Blood
 - Phase I groups – do not want child to be poked
 - Phase II groups – not as opposed except one Asian group sees blood as "precious source of life"
 - Hair samples
 - Phase I groups had no problems
 - Phase II groups – worries over Voodoo, cultural reasons

Placeholder for copyrighted image.

Keeping You Interested

Themes heard across all groups

- Monetary incentives preferred
- Most participants want all of test results ASAP after visit
- Would like to receive periodic Study updates

Barriers to Participation (Phase II Focus Groups Only)

- Mistrust of researchers and federal government
- Afraid Study would target minorities (African American and one teen group)
- Afraid conducting "secret" research (American Indians, teen group)
- Use of biospecimens for drug testing and fear results go to:
 - Law enforcement agencies or insurance companies
- Language (Mexican Americans and one group of Asians)
- Transportation

Overcoming Barriers to Participation

- Guarantee of confidentiality
 - Only Study staff see results
 - Will not release to insurance or law enforcement agencies
- Endorsement by organizations
 - Respected and trusted, national as well as local, community organizations, Tribal leadership
- Make clear participation is from all racial/ethnic groups – no group was singled out or excluded

Impact

Focus group provided insights into participants' decision making process. These results will help with the plan and design protocols for the National Children's Study to maximize participation while minimizing selection bias and loss to follow-up.

